

White Paper ■

Guideposts to the Future—An Agenda for Nursing Informatics

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Abstract As new directions and priorities emerge in health care, nursing informatics leaders must prepare to guide the profession appropriately. To use an analogy, where a road bends or changes directions, guideposts indicate how drivers can stay on course. The AMIA Nursing Informatics Working Group (NIWG) produced this white paper as the product of a meeting convened: 1) to describe anticipated nationwide changes in demographics, health care quality, and health care informatics; 2) to assess the potential impact of genomic medicine and of new threats to society; 3) to align AMIA NIWG resources with emerging priorities; and 4) to identify guideposts in the form of an agenda to keep the NIWG on course in light of new opportunities. The anticipated societal changes provide opportunities for nursing informatics. Resources described below within the Department of Health and Human Services (HHS) and the National Committee for Health and Vital Statistics (NCVHS) can help to align AMIA NIWG with emerging priorities. The guideposts consist of priority areas for action in informatics, nursing education, and research. Nursing informatics professionals will collaborate as full participants in local, national, and international efforts related to the guideposts in order to make significant contributions that empower patients and providers for safer health care.

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Background

Nursing informatics has been defined by McCormick as “. . . an applied science”¹ and by the 2001 American Nurses Association Scope and Standards of Nursing Informatics as a specialty that:

integrates nursing science, computer science, and information science to manage and communicate data, information, and knowledge in nursing practice. Nursing informatics facilitates the integration of data, information, and knowledge to support patients, nurses, and other providers in their decision-making in all roles, and settings. This support is accomplished through the use of information structures, information processes, and information technology.²

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The roles of health care providers, including nurse informaticians, are diversifying. Nurses with advanced education in informatics work as project managers, consultants, product developers, decision support and outcomes managers, chief information officers (CIOs), advocates/policy developers, entrepreneurs, and business owners in industry. In academic environments, nurses with advanced informatics education include researchers, educators, and advocates/policy developers. Administrative nurses and nurse-CIOs purchase large information systems within all health care markets. Health information technology vendors employ nurses in senior executive roles, such as Chief Nursing Officer (CNO), to provide vision and management for implementation of clinical systems. Nurses work in private sector and clinical environments as systems analysts, requirements analysts, content developers, database administrators, implementation specialists, information system liaisons, trainers, and use case scenario managers. The Web sites of the American Medical Informatics Association (AMIA), the Healthcare and Information Management Systems Society (HIMSS), and the Capital Area Roundtable in Nursing Informatics (CARING) post many job offerings for nurses with informatics knowledge.

Context—The Environment

Nursing professionals must recognize and monitor environmental changes that generate new markets and domains for health care informatics. The anticipated changes relate to: demographics, health care quality and costs, health care informatics, the potential impact of genomic medicine on clinical practice, and the impact of new threats to society.

Demographics

Future demographic changes will alter the face of health care. The U.S. Census Bureau in March 2004 predicted that, between 2010 and 2020, the U.S. population aged 65 or older will increase by 14,388,000 persons, while the number of 20- to 64-year-olds will grow by 6,830,000.³ In addition, providing care to a more culturally diverse population will challenge traditional health care delivery mechanisms. Projected population shifts from 2010 to 2020 include fewer non-Hispanic whites (decreasing from 65.1% to 61.3% of the U.S. population) and increases in all other groups.⁴ Thus, the major demographic shifts are for an older and more diverse society.

Health Care Quality

Improving the quality of health care will continue to be a national priority. Consumers will continue to demand accountability from providers. For example, CMS's Home Health Compare Web site indicates differences in outcomes among care providers in different health care facilities.⁵ Efforts to use Medicare, its Quality Improvement Organizations (QIOs), and its demonstration projects to tie payment to improved quality for beneficiaries will continue. Many believe that Medicare can be a catalyst for measuring and improving health care quality across the country, with information technology facilitating quality measurement and enhancement. MedPAC's recommendation of budget neutral pay for performance programs is a step toward rewarding providers who improve quality.⁶

Cost of Delivering Health Care

Persistent health care problems include: inequities in the cost of care, practice variations, less than ideal capacity to provide care, duplication of efforts, and unequal access to care. The total costs of health care are currently a burden to individual patients and to society as a whole. Current costs were estimated at \$1.7 trillion by Centers for Medicare and Medicaid Services.⁷ In 2004, 15.6% of the U.S. population was uninsured.⁸ As the cost of health care continues to increase, the numbers of uninsured will likely increase as well. The need for nurses will intensify, with some states like Ohio and California projected to have huge demands for more nurses, ranging from an anticipated shortage of 32,000 in Ohio to 122,000 in California by 2020.⁹

Health Care Informatics

Ongoing technological developments will influence health care delivery. Experts in nursing discussed anticipated impacts of worldwide changes in hardware (such as greater use of laptops and PDAs), software (such as computerized decision support software, CDSS), and other technologies used by nurses.^{10,11,12} Bioinformatics, including computational biology and biotechnology, will evolve to support new developments in the genetic, genomic, proteomic, metabolomic, and comparative translational sciences.¹³ More nurses will need to be trained in the use of biomedical informatics and computational biology.

Genetic Discoveries

Advancing knowledge of genes, genomes, and proteomes will certainly influence future health care at all levels: prevention of disease, diagnosis of disease, and personalized treatment of individuals' diseases. New models must integrate biomolecular information into the electronic health

records used by caregivers and patients. Personal health records (PHRs) replete with patients' self-provided information, such as family histories, will inform predictions of risks, selections of cures, prevention of adverse events, and optimizing responses to treatments.¹⁴ Integration of genomic information into health care will require dramatic changes that create new, robust informatics infrastructures.

Threats to Society

Two major threats to society include bioterrorism and infectious disease pandemics. Events following 9/11/2001 have increased the need for an information infrastructure for disease-outbreak-related communication and detection. The Centers for Disease Control and Prevention (CDC) proposed information infrastructure, Public Health Information Network (PHIN), recommends standards for interoperability at the local, state, and national level.¹⁵ The CDC is also developing the National Electronic Disease Surveillance System (NEDSS) to detect outbreaks.¹⁵ The Agency for Healthcare Research and Quality funds new informatics solutions, including decision support systems, syndromic surveillance systems, Regional Health Information Organizations (RHIOs), and clinician response networks.¹ The Health Resources and Services Administration (HRSA) has promoted informatics educational solutions.¹ Additional resources to address threats to society have recently been described.^{16,17}

Informatics applications for biodefense can be utilized and expanded at the state and local levels to monitor and respond to naturally occurring outbreaks, such as pandemic influenza.¹⁷ In related developments, syndromic surveillance systems are being linked to convey electronic health data from emergency rooms to regional laboratories and the CDC.¹⁸

Within society, health care challenges will shift from acute conditions, such as infections, to more chronic health conditions related to cardiovascular diseases, cancer, behavioral disorders, and lung disease. Much of health care delivery in 2020 will be ambulatory and community based for these chronic health conditions.

Resources to Align Informatics Locally and Nationally

Since passage of the Health Insurance Portability and Accountability Act in 1996, actions by the U.S. Congress, the federal government, and its advisory bodies, especially the National Committee on Vital and Health Statistics (NCVHS), have exerted a steadily increasing influence on health care informatics. The provisions of the Medicare Modernization Act of 2003 and the 2004 Presidential appointment of a National Coordinator for Health Information Technology continued this trend. Previously described CDC and AHRQ initiatives, such as PHIN and RHIOs, are representative of new government-funded informatics solutions.

In 2005, the Hurricane Katrina-related disaster highlighted the need for an information infrastructure for communication and the value of electronic health records in ensuring continuity of care for displaced populations. Recent efforts by the Secretary of Health and Human Services and the Office of the National Coordinator to promote development of the National Health Information Network and to establish

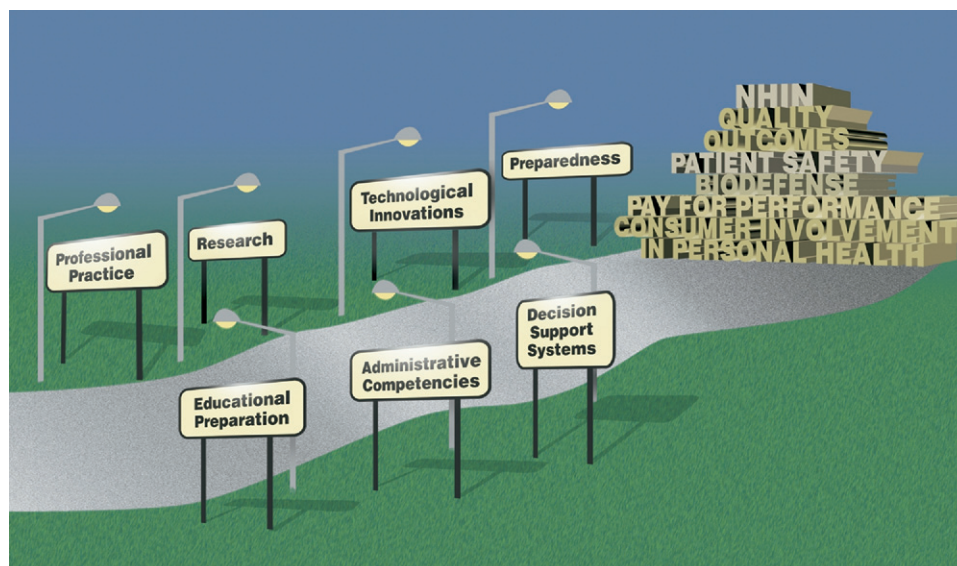


Figure 1. Targets and guideposts for future nursing informatics initiatives.

sustainable processes for harmonizing standards, certifying electronic health record systems, and promoting widespread adoption of electronic health records impact health care informatics priorities.¹⁹ Several health information technology bills emphasizing health data standards have been introduced in the current Congress. Recent legislative efforts also include financial incentives for the use of electronic health records.

Guideposts toward the Future

Figure 1 summarizes the authors' view of the current healthcare environment, with targets and guideposts for future nursing informatics initiatives. The guideposts can help to 1) identify required informatics solutions, 2) describe education and research needs for nursing informatics practice and administration, and 3) encourage nurses to collaborate as full members in local, national, and international activities. The guideposts will change over time, and merit discussion by the broader health care informatics community. Subsequent meetings are planned to refine recommendations made in this white paper.

Nursing Guideposts to Contribute in Developing Informatics Solutions

Group consensus at the meeting emphasized that nurses must play key roles in developing information systems so that the systems improve the quality of care. Authors agreed that health care would remain patient-focused, with relevant emerging activities such as development of personal health records (PHRs).²⁰ Nurses have had longstanding involvement in developing consumer-focused applications, including decision support tools. They will contribute to development of PHRs as individually held and controlled life-long health information repositories. Projects are underway in the industry to establish PHR for employees to monitor their laboratory and medication profiles. Anticipated PHR-related advances include 1) capturing all clinical encounters; 2) health promotion activities; 3) monitoring personally valued health parameters such as exercise, nutrition, and spiritual

well-being; 4) implementing decision support, risk management, and professional advice; 5) providing consumer-focused health information and education; 6) managing health-related benefits and financial resources; and 7) monitoring environmental exposures and other community health information.²¹ Future activities that must involve nurses include development of frameworks and templates for the PHR; issues of electronic health record and decision support system content; system-delivered guidelines; development and distribution of consumer best practice information; health informatics-related education; and, issues of health care and information system access control.

Nursing informatics should encompass emergency preparedness, biodefense, and public health nursing.¹⁶ The future of nursing informatics will be impacted by the genomic revolution.¹⁴ Since nurses serve as genetic counselors in many environments, nurses must stay informed about computational biology, genomics, and proteomics to help engineer emerging bioinformatics applications.

Guideposts for Nursing Informatics Education

Many future nursing informatics guideposts involve education. Educational programs must prepare nursing students to work in multidisciplinary teams. Future nurse informaticians will be professional knowledge workers who will employ advanced information technologies and new health care information content to help to create and evaluate innovative solutions that coordinate future health care delivery by care teams. New nursing information management systems must be developed to help nurses evaluate workflow, assess risk, plan care strategies, and evaluate outcomes. Inherent in this process is a critical need to develop Evidence Based Nursing (EBN) knowledge, which is underway through numerous collaborations with university and other health care organizations and industry. The electronic health record vendor community can contribute by partnering with academic centers, to create curriculums that teach EBN embedded in EHR-related content and processes. This will enhance nurses developing new skills as knowledge

workers with expertise in clinical decision support. Such a vendor-based strategy can build a nurse community/vendor industry model network. Frameworks to embed the Nursing Minimum Data Set (NMDS) and the Nursing Management Minimum Data Set (NMMDS) into the EHR provide another nursing data model focused on the continuum of health care.

As more students seek nursing informatics curricula, there are too few faculty members to support this academic endeavor. Nursing educators must plan creatively how to educate these students. In conjunction with the growth of informatics programs both nationally and internationally, nursing educators should collaborate with other informaticians to reflect upon the nature and scope of graduate preparation in informatics.

The AMIA-NIWG, recognizing the need to identify the diverse existing graduate content, established a 17-member task force on nursing informatics curriculum. The purpose of this initiative was to reach consensus on the necessary requirements of a master's level informatics program that is reflective of the American Nurses' Association's (ANA) 2001 Scope and Standards of Nursing Informatics Practice. At least 12 master's programs exist in the United States that offer a nursing informatics major. These programs prepare informatics specialists who are able to apply theory to analyze the need for health information systems, and design, implement, evaluate, and maintain health information systems. All programs offered both full and part time study. Only a few programs were totally available online. The average number of credits to complete a master's degree was 40 credits with the lowest being 36 and the highest being 45. The average number of credits for core courses required in all master's students was 12 with a range from 8 to 18 credits. The number of credits allocated for required informatics courses, not including practicum credits, ranged from 7 to 27 credits with the average being 13.87 credits. The number of credit hours allocated to practicum ranged from 3 to 6. Several universities (e.g., Utah, Maryland, Iowa, and Arizona) offer a PhD in nursing informatics. These students are prepared as informatics scientists, to prepare additional nurse informatics specialists, as well as develop further the emerging science in the field. Their education incorporates computer science, information science, and nursing science, as well as human-computer interaction, organizational theory, and project management. Finally, nine universities offer certificates (either postbaccalaureate or postmaster's) in nursing informatics.

Nurse informatics specialists work in health care agencies (hospitals, home care, and public health), industry, or education. Some are entrepreneurs. Because more and more nurse informatics specialists are working in public health, more educational programs are expected to incorporate public health informatics.

Guideposts to Support Nursing Informatics Research

The previously published Agenda for Nursing Research is outdated.²² The profession needs a federally funded research agenda that is both responsive to current and future health care priorities, as well as building the nursing informatics science needed to design technology that can truly

enhance our capacity to deliver effective nursing care across the continuum. Possible innovations include, but are not limited to, supporting evidence-based practice through the Electronic Health Record (EHR) and generating new nursing knowledge through techniques such as data mining. In addition, new evidence-based methodologies for analyzing, designing, implementing, and evaluating systems are needed.

As guideposts to the future, the group recommended areas that will require nursing informatics research involvement on topics such as:

1) secondary use of clinical data; 2) security including the use of biometrics, signatures, encryption, and Public Key Infrastructure (PKI); 3) aggregation of patient data without use of identifiers; 4) promoting the use and development of standards; 5) population health; 6) privacy and confidentiality; and 7) a focus on an NHIN. Additional issues and trends that should be monitored include: NCVHS studies of population changes related to race and ethnicity; financial issues, such as methodologies for using large federal databases through the gateway Web site (<http://hhs-stat.net>); and appropriate use of Geographic Information Systems (GIS).

More federal research and training resources will be needed. Nursing informatics should focus on obstacles and opportunities related to health care quality including: 1) assessing and improving health care and health outcomes; 2) reducing disparities in health care for minorities; 3) building the data infrastructure to support quality assessments and improvement; and 4) balancing patients' interests in privacy protection and protection of their health and safety.

Nursing has much to gain from engaging in the state-of-the-science initiatives addressed in the NIH Roadmap. Application of emerging sophisticated data analysis techniques can increase the capacity for knowledge development in ways never before seen.^{23,24} Nursing is especially well positioned to contribute to the new approaches to discovery, interdisciplinary approaches to research, and expanding the capacity for clinical research. Nurses staff the majority of Clinical Research Organizations (CROs) and many clinical research trials. The nursing profession's investments in knowledge representation, technology-mediated patient care interventions, and robust tools for knowledge development and dissemination are integral to the science of NIH and the Roadmap. In particular, nursing's capacity to characterize patients' experiences and represent these experiences in standardized language is unparalleled in peer disciplines. Nursing's research in empowering the largest group of health care practitioners and families to actively participate in health and health care is similarly critical.

Using standardized vocabularies within the Roadmap initiative will empower the work of the NMDS, international standards development and adoption, and the seamless flow of knowledge and health care across the biomolecular and sociocultural dimensions of humans and the systems within which they receive care.

Nurses should be regular contributors to responses to federal Requests for Information (RFIs) on health information technology and related policy responses that are regularly issued by governmental agencies. Several of these have had, and will have, implications not only for information tech-

nology, but also for advanced practice nursing. For example, in the e-prescribing RFI, only doctors were mentioned even though nurse practitioners and anesthesiologists also prescribe. The AMIA NIWG should develop a process for responding to RFIs that impact health care information technology

Opportunities for Collaboration

Opportunities exist for nurses to play key roles in the work initiated by the Office of the National Coordinator for Health Information Technology (ONC).¹⁹ Nurses should also design, monitor, implement, and respond to standards proposed by the Consolidated Health Informatics (CHI) initiative,²⁵ the Federal Health Architecture work,²⁶ and security programs in the National Institute of Standards and Technology (NIST).²⁷ Some of the projects impacting on nursing informatics will be: interoperability, e-prescribing, and Pay 4 Performance, the Electronic Health Record (EHR) and the Regional Health Information Organizations (RHIOs). Responding to these new external directions will demand new administrative competencies in nurses involved in informatics and more multidisciplinary collaborations.

The authors recommended that AMIA Nursing Informatics Working Group (NIWG) maintain a liaison to the National Committee for Vital Health Statistics (NCVHS). NCVHS provides outreach of information about government initiatives to the private sector, and advises the Secretary of Health and Human Services and Congress in the area of health information. The acceleration of uniform data standards and protections of privacy and security are goals of the NCVHS. Members also advise the government on the implementation of Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Medicare Modernization Act of 2003 (MMA).

The AMIA NI-WG is the official U.S. representative to the International Medical Informatics Nursing Informatics Special Interest Group (IMIA-NIsig). The AMIA NI-WG elects a person to participate in the IMIA-NIsig. The NIsig supports numerous international informatics initiatives, including the design and implementation of standards.

In addition, the AMIA NI-WG has established liaisons to several organizations including a linkage between the American Association of Colleges of Nursing (AACN) and AMIA. Informatics competencies, information management, and information systems applications as core to quality and outcomes permeate the Clinical Nurse Leader (CNL) initiative as well as the Doctor of Nursing Practice (DNP) initiative. Moreover, liaison with the American Association of Nurse Executives (AONE) is essential to the advancement of selection, efficient implementation, and effective use and evaluation of clinical information systems. The American Academy Nursing (AAN) Informatics Expert Panel is also guided through NI-WG liaison activities.

The Alliance for Nursing Informatics (ANI) is another example of effective leveraging of informatics capacity across all specialties and initiatives within nursing. There is currently over 20 nursing informatics organizations in this country (some regional; others national) representing over 3,000 nursing informatics specialists. These nurses are represented through the Alliance for Nursing Informatics (ANI)^{1,28} co-sponsored and funded by the American Medical Informatics Association (AMIA) and the Health Informa-

tion and Management Systems Society (HIMSS). More than 20 liaison relationships support the diffusion of informatics throughout specialties as well as inform the development of informatics by the broader nursing expertise.

Nursing informatics must develop a visible, recognized professional presence. Industrial labor codes are needed for persons working in informatics. Industry classifications provide coding structures that classify the types of work that the nurses working in informatics are performing. A request for modification to the Standard Occupation Codes was drafted by a NIWG task force, approved by the NIWG and then by the AMIA Board, and subsequently submitted to the Department of Labor in June 2005. A letter of support from HIMSS accompanied the request.

Data from several sources supported the request. For example, HRSA's 2000 National Sample Survey reports that, of their sample of 29,394 registered nurses, 109 (0.4%) listed their primary nursing job as informatics nurse.²⁹ The researchers extrapolated from that sample that there were 8,406 informatics nurses in the U.S. population in 2000. The 1992 and 1996 reports for the same survey listed no informatics, which speaks to the rapid growth of this new field. Still, some informatics nurses have been practicing in this area since the 1980s. Today, there are nurse informaticians in executive level positions in the industry, as well as in healthcare organizations (as CIOs, for example).

Summary

This white paper describes major influences changing health care that require the nursing informatics profession to alter its course and set new directions. The resources available to nurses for such work have been discussed. Guideposts have been described to help the nursing informatics professionals to improve health care delivery, educate new professionals, and conduct research. Recommendations for multidisciplinary liaisons and policy involvement required to make this journey have been made.

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